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Medicaid 1915(c) Home and Community-Based Services Waivers Across the States

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This article provides State-level data on the Medicaid 1915(c) home and community-based services (HCBS) waivers program. Medicaid 1915(c) waiver participants were 32 percent of the Medicaid participants in institutional care in 1997. These data document wide interstate variation in organizational oversight and program policies for the waivers. Many structural barriers to HCBS waiver growth existed. Case management services, in some form, were normative for most HCBS waiver participants, but formal mechanisms to assess client satisfaction and service quality were less common. Substantial new growth in this program may require fundamental changes in HCBS waiver policies.

INTRODUCTION

The purpose of this research was to systematically describe the Medicaid 1915(c) HCBS waivers across the States. States also have the option of offering HCBS via other programs, e.g., the Medicaid Title XIX Personal Care Services (PCS) optional State plan benefit (LeBlanc, Tonner, and Harrington, to be published), the Medicaid Home Health benefit, the Medicaid Early and Periodic Screening, Diagnostic, and Treatment Program (EPSDT), and programs supported with State general funds designed for those who do not qualify for Medicaid, which were excluded from the present study. Emerging publications have addressed issues surrounding the numbers of program participants and related expenditures in the waiver and other HCBS programs, but few have paid close attention to program administration. Therefore, little is known about how the States vary in their development of waivers, selection of target populations, administrative structure, and program policies. By "administrative structure," we are referring to ways in which the States have arranged for oversight of a waiver or waivers within an array of agencies, offices, and other organizations. Program policies include those pertaining to eligibility, cost caps, service limits, and program monitoring and assessment.

The Medicaid HCBS waiver program was established with the passage of section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. Section 2176 created section 1915(c) of the Social Security Act, which authorized States to request the option of providing home and community-based alternatives to institutional care (Miller, 1992; Miller, Ramsland, and Harrington, 1999). Many of the first waivers were targeted toward the aged and disabled or those with developmental disabilities, but in recent years, waivers have evolved to target Medicaid-eligible persons with a variety of conditions and chronic disorders, such as physical disabilities, acquired immunodeficiency syndrome

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(AIDS), acquired brain injuries and other forms of severe disability, including, to a limited extent, chronic mental illness (Miller, 1992; Miller, Ramsland, and Harrington, 1999; Harrington et al., 2000a). The waiver program allows States the opportunity to make available a wide range of non-medical services inherently related to personal assistance, including case management, personal care services, homemaker and chore services, adult day care, transportation, and respite and companion services.

Because the 1915(c) waivers were created to offer alternatives to institutionalization, program regulations require HCBS to be offered only to those who are eligible for institutional placement (42 C.F.R. 440.180). Moreover, the States are allowed to target waivers to particular populations. Consequently, unlike optional State plan benefits, they do not require that services be made available to all categorically or medically needy groups. (This is called a waiver of comparability.) Finally, the States also must specify, for each waiver, a limit on the number of individuals who may receive benefits (42 U.S.C. 1396n, section 1915(c)(4)(A)). (These number limits are commonly referred to as "slots.") States have the option of limiting waiver services to targeted geographic regions as well (42 C.F.R. 441.351, part H), which also distinguishes the waivers from other Medicaid services offered as optional State plan benefits (e.g., Title XIX personal care services) (LeBlanc, Tonner, and Harrington, to be published).

States have the option of setting financial eligibility criteria for the 1915(c) waivers at the same level as those for institutional placement, up to 300 percent of Supplemental Security Income (SSI), although this varies at the States' discretion (Horvath, 1997; Bruen et al., 1999). Service-need criteria for the waivers may be no more liberal than need criteria for institutional placement under Federal statute (42 C.F.R. 441.302(c)) but may be more restrictive, at the option of each State. Need criteria for institutional placement differ from State to State, and consequently, so do criteria for the waivers (Tonner, Harrington, and LeBlanc, to be published).

The 1915(c) HCBS waivers are required to be, by statute, cost-neutral. The program was designed to provide a cost-neutral alternative to institutional care, requiring the States to keep waiver costs at or below those of comparable institution-based service.

Shortly after their inception, the HCBS waiver program became a topic of interest among health care and health policy researchers alike (Laudicina and Burwell, 1986; Miller, 1992). These and more recent studies have begun to describe the breadth and depth of the waivers more fully, typically offering statistics on State and national trends (Litvak and Kennedy, 1991; Burwell, 1999; Harrington et al., 2000a; Miller, Ramsland, and Harrington, 1999), or documenting the statutes and regulations that shape the benefits (Harrington et al., 2000b). Some have begun to test State-level predictors of waiver participants and expenditures (Harrington et al., 2000c). Researchers have also conducted indepth studies of select States to test the cost-effectiveness of the 1915(c) HCBS waivers in comparison to the costs associated with institutional care, producing mixed results (Vertrees, Manton, and Adler, 1989; Alecxih et al., 1996).

With some foundation of an understanding for the statistical trends on 1915(c) HCBS waiver participants and expenditures, analysts are beginning to look beyond the numbers, toward an array of issues concerning waiver policy and service outcomes. The administrative structures that underlie this joint Federal-State

benefit program have received relatively little attention to date. Some have focused on specific services such as personal care (LeBlanc, Tonner, and Harrington, to be published) and case management (Gilson and Casebolt, 1997; Micco et al., 1995), as well as the potential benefits of consumer-directed models of care (Beatty et al., 1998; Benjamin, 1998; Dautel and Frieden, 1999; Doty, Kasper, and Litvak, 1996; Scala, Mayberry, and Kunkel, 1996), while others have examined issues related to specific populations targeted for waiver services (e.g., Anderson and Mitchell, 1997; Buchanan and Chakravorty, 1997; Degenholtz, Kane, and Kivnick, 1997; West et al., 1999). The present research focuses more explicitly on some of the ways in which the 1915(c) waivers are administered and regulated by the States.

METHODS

Data were predominantly collected from telephone interviews with State officials who work closely with the 1915(c) waiver programs. Initial telephone calls to each State's office of Medicaid were made to identify the appropriate persons to be interviewed. It was our goal to locate individuals who worked somewhere between the front lines of service delivery and the upper levels of policy planning. Most of those interviewed held jobs with titles including terms such as specialist, analyst, manager, administrator, supervisor, or coordinator. A small number worked as departmental or program directors. In States with many waivers, a person knowledgeable about the waiver program as a whole was interviewed. In such instances, followup with additional contacts for specific details about particular waivers was also carried out.

All interviews were conducted between fall 1998 and summer 1999. Data were collected from officials in all 50 States and Washington, DC. Interviews lasted, on average, 42 minutes. In five States, in-person interviews were carried out as part of site visits for a related study.

The structured interview protocols included a series of questions regarding the agencies that administered the waivers, the eligibility criteria used for the waivers, and the types of formal limits placed on waivers in terms of costs and hourly limits. The survey also asked about the case management services provided and programs for monitoring client satisfaction and quality.

Medicaid financial eligibility data collected via the surveys were compared with two recent reports (Horvath, 1997; Social Security Administration, 1999) for accuracy. In addition, data from HCFA Forms 372, 2082, and 64 were used to provide additional statistical data and points of reference. Form 372 data showed participant and expenditure data for the 1915(c) waivers and for case management services within the waivers. Form 2082 data showed the numbers of participants in nursing homes and intermediate care facilities for the mentally retarded (ICFs-MR). Form 64 data showed the expenditures for Medicaid targeted case management offered by the States via the State plan option for comparison with case management in the waivers.

These State-level data were not adjusted for sociodemographic or other factors that may influence patterns of Medicaid service use.

RESULTS

Size and Administrative Structure

Table 1 shows a ranking of the States with regard to the size of their waiver programs, including the total number of waiver participants, nursing home or ICF-MR

Table 1

Medicaid 1915 (c) Home and Community-Based Services Participants, by State: 1997

State	Total Waiver Participants	NH/ICF-MR Participants per 1,000 Population	Waiver Participants per 1,000 Population
Total	561,510	—	—
Oregon	25,665	0.13	7.91
Kansas	15,392	7.12	5.92
Rhode Island	5,712	10.58	5.79
Missouri	23,823	7.00	4.41
Vermont	2,264	6.61	3.84
Colorado	14,243	5.30	3.66
Wisconsin	19,006	8.81	3.65
Wyoming	1,744	5.63	3.63
South Carolina	13,281	5.06	3.51
Minnesota	16,379	9.11	3.49
Washington	19,364	4.23	3.45
Arkansas	8,355	9.36	3.31
North Dakota	2,089	9.82	3.26
Kentucky	12,125	7.44	3.10
Illinois	36,743	7.94	3.06
New Hampshire	3,489	6.37	2.98
Connecticut	9,629	14.04	2.95
West Virginia	5,257	6.76	2.90
New York	51,986	8.03	2.86
South Dakota	1,860	9.02	2.52
Ohio	27,115	8.46	2.42
Alabama	10,396	5.44	2.41
Montana	2,120	6.80	2.41
Iowa	6,022	9.85	2.11
Georgia	15,199	5.46	2.03
Maine	2,527	6.33	2.03
Massachusetts	12,242	9.27	2.00
Virginia	13,449	4.43	2.00
Florida	27,124	5.08	1.85
Nebraska	3,069	12.15	1.85
New Mexico	3,014	4.62	1.75
North Carolina	12,898	6.35	1.74
Texas	29,598	5.66	1.53
Alaska	915	2.87	1.50
California	46,718	4.11	1.45
New Jersey	11,703	6.71	1.45
Oklahoma	4,697	8.96	1.41
Utah	2,861	3.07	1.39
Delaware	951	4.64	1.29
Idaho	1,305	4.46	1.08
Michigan	9,753	4.82	1.00
Hawaii	1,129	3.40	0.95
Pennsylvania	10,900	6.89	0.91
Nevada	1,515	2.49	0.90
Mississippi	2,036	7.49	0.75
Maryland	3,741	5.34	0.73
Tennessee	3,747	9.33	0.70
Louisiana	2,736	9.34	0.63
Indiana	3,624	8.97	0.62
Arizona[1]	—	4.03	—
Washington, DC[2]	—	10.53	—
Mean	11,459	6.51	2.1

[1] Medicaid 1115 waiver.

[2] Waivers not yet active.

NOTES: Figures are not unduplicated. NH/ICF-MR is nursing home or intermediate care facility for the mentally retarded.

SOURCES: Health Care Financing Administration: Form 372 and Form 2082. U.S. Bureau of the Census, 1997.

participants per 1,000 population and waiver participants per 1,000 population. The States are ranked on this last element. There were a total of 561,510 participants in the program in 1997. The average number of waiver participants was 2.10 per 1,000 population across the States, ranging from a high of 7.91 in Oregon to a low of 0.62 in Indiana. In contrast, there was an average of 6.51 participants per 1,000 population living in institutions (nursing facilities and ICFs-MR). On average, States served

about 32 percent as many participants in the HCBS waivers as were served in the nursing home or ICF-MR facilities. Only Oregon funded larger numbers of participants in the home and community than in institutions.

Every State administered at least two 1915(c) waivers in 1998-1999, with the exception of Arizona, where all Medicaid HCBS were rendered by means of an 1115 managed care waiver.[1] The mean number of waivers within each State was 4.6, with a high of 10 in Colorado and a low of 2 in a handful of States (Massachusetts, Montana, Oregon, Washington, DC, and West Virginia). The number of waivers in a State was not necessarily associated with the total number of waiver participants.

There were 231 approved waivers nationwide in 1998-1999, more than one-half of which were targeted toward persons with mental retardation/developmental disability (MR/DD) (77) or the aged/disabled (46). Other groups selected for waivers were the physically disabled (33); the aged/elderly (23); children (special care) (19); persons with AIDS or AIDS-related conditions (15); people suffering traumatic brain injury (TBI) or other head injury (15); and persons with serious mental illness (3). Every State offered both an MR/DD and aged/disabled or aged waiver in 1988-1999. Waivers for persons diagnosed with serious mental illnesses were quite rare, in part because of the States' strict interpretation of the Federal regulation stipulating an institutional comparison group for waiver creation. Because Medicaid funding is not allowed for persons age 18-64 in institutions for mental disease, State officials reported they find it more difficult to justify this type of waiver.

[1] A list of 1915(c) Medicaid HCBS waivers across the 50 States and Washington, DC, for 1998-1999, the population targeted, the administering agency or agencies, and the number of participants served in each waiver during 1997 (the most recent year with available participant data) is available from Allen J. LeBlanc (address at the end of this article).

Based on 1997 data only, the average Medicaid 1915(c) waiver in the United States served 2,661 people, although in 1998-1999 they ranged from those serving only a few participants to those serving 20,000 and more.

With regard to administrative structures the States use to manage their waiver programs, the average number of administering agencies per State was 2.4. A single agency held administrative responsibility for all active 1915(c) HCBS waivers in 12 States. Sixteen States used 2 administrative agencies; 15 States used 3; 7 used 4 or more. Further, the data illustrate that only 64 of the total 234 active waivers (27 percent) in 1998-1999 were administered directly by a State office of Medicaid.

Program Financial Eligibility[2]

Most States coordinate Medicaid financial eligibility with eligibility for SSI for low-income individuals who are aged, blind, or disabled. This is the case for 39 States and Washington, DC. Eleven States (Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, North Dakota, New Hampshire, Ohio, Oklahoma, and Virginia) were 209(b) States in 1998-1999, meaning they had elected to retain provisions of their 1972 Medicaid programs that were more restrictive than the SSI eligibility criteria. Thus, 209(b) States may use more restrictive Medicaid eligibility criteria than those of the SSI program. Federal Medicaid rules also require Medicaid coverage for other low-income groups and require a limit on assets.

The Federal SSI benefit level for a single individual was $500 per month in 1999. States have the option of providing State supplementary payments (SSPs). Twenty-six of the States offered some SSPs,

[2] State-level data on eligibility rules for institutional care and for HCBS waivers are available from Allen J. LeBlanc (address at the end of this article).

although most of those offered only a modest sum for individuals living independently in the community. Some added no more than $15 per month (Hawaii, Maine, Michigan, South Dakota, and Wyoming). Some States offered higher SSP rates for individuals living in residential care or other congregate living settings. In contrast, 25 States used only the Federal SSI benefit.

Thirty-four States operated a medically needy program in 1998-1999. This allowed the extension of Medicaid eligibility to individuals and families having incomes in excess of the State's prescribed standard to reduce excess income by "spending down." Seventeen States did not have such a program.

Most States adopted the Medicaid special income rules for institutional placement, allowing up to 300 percent of SSI for the categorically needy. Fourteen States had Medicaid eligibility income standards below 300 percent of SSI for the categorically needy. States may also have different special income rules for those that are medically needy than for those that are categorically needy under the Federal rules. States also have spousal impoverishment rules that allow for the separation of assets for those in institutions.

Comparing special income rules for waiver eligibility, 44 States had income rules for the HCBS waivers that were the same as those for institutional placement in 1998-1999. In the remaining seven States (with the exception of Arizona, which operates an 1115 waiver), waiver eligibility was tied to a lower income standard for at least some waivers (Alabama, Connecticut, Idaho, Maryland, Mississippi, Utah, and Washington, DC). In these States, it was consequently more difficult for applicants to qualify for waiver services than for institutional care.

Finally, 12 States had at least one HCBS waiver that was not statewide in scope. In addition, an unknown number of waivers intended to be statewide are in reality limited to select geographic regions, partially due in some States to a shortage of available providers (Harrington, LeBlanc, and Tonner, 1999; LeBlanc, Tonner, and Harrington, to be published). Therefore, the degree to which statewide coverage is actually achieved for many waivers remains unclear.

Cost Caps and Formal Limits on Service

Table 2 contains data on cost caps (ceilings) and formal limits on services imposed in the waivers. All 1915(c) waivers are required by Federal statute to be cost-neutral and, as a result, all States reported using cost caps as a means of controlling program expenditures.

The form of these caps, however, differed across the States. Fifteen States used the aggregate-level cost controls for each active waiver and thus did not enforce individual cost caps on participants. With aggregate cost caps, some program participants receiving waiver services could exceed the costs of comparable institutional care. However, all State officials stated that their waivers remained cost-neutral despite these exceptional cases. Some States used less than 100 percent of total institutional costs for the aggregate cost cap; for example, Illinois used a cap of 80 percent of the average nursing home rate.

Another cost-containment strategy was the use of cost caps applied at the individual level. Seven States enforced cost limits for individual participants. In the remaining 28 States, a combination of aggregate and individual cost caps was used, varying waiver to waiver (Table 2). To illustrate, New Jersey adopted aggregate cost caps in

Table 2

Formal Limits and Cost Caps Placed on Medicaid 1915(c) HCBS Waivers: 1998-1999

State	Cost Caps[1]	Formal Limits[2]
Alabama	Aggregate	Some
Alaska	Aggregate	No
Arizona	Individual[3]	No[3]
Arkansas	Individual/Aggregate	No
California	Aggregate	No
Colorado	Individual/Aggregate	No
Connecticut	Individual	No
Delaware	Individual	No
Florida	Individual/Aggregate	Some
Georgia	Individual/Aggregate	Some
Hawaii	Aggregate	No
Idaho	Individual	No
Illinois	Individual/Aggregate	No
Indiana	Individual/Aggregate	No
Iowa	Individual	Some
Kansas	Individual/Aggregate	Some
Kentucky	Aggregate	Some
Louisiana	Individual/Aggregate	Some
Maine	Individual/Aggregate	Some
Maryland	Individual/Aggregate	Some
Massachusetts	Aggregate	No
Michigan[4]	Aggregate	All
Minnesota	Individual/Aggregate	Some
Mississippi	Aggregate	No
Missouri	Individual/Aggregate	No
Montana	Aggregate	No
Nebraska	Individual/Aggregate	Some
Nevada	Individual/Aggregate	No
New Hampshire	Aggregate	No
New Jersey	Individual/Aggregate	Some
New Mexico	Individual/Aggregate	Some
New York	Individual	No
North Carolina	Individual	No
North Dakota	Individual/Aggregate	No
Ohio	Individual/Aggregate	No
Oklahoma	Individual/Aggregate	Some
Oregon	Individual/Aggregate	No
Pennsylvania	Individual/Aggregate	Some
Rhode Island	Individual/Aggregate	Some
South Carolina	Aggregate	Some
South Dakota	Individual/Aggregate	No
Tennessee	Aggregate	No
Texas	Individual/Aggregate	No
Utah[4]	Aggregate	All
Vermont	Aggregate	No
Virginia	Individual/Aggregate	No
Washington	Aggregate	No
Washington, DC	Individual	No
West Virginia	Individual/Aggregate	No
Wisconsin	Individual/Aggregate	No
Wyoming	Individual/Aggregate	No

[1] Individual/aggregate means that some waivers cap aggregate costs, some cap individual costs.

[2] Some means hourly or daily limits on some services or waivers.

[3] Medicaid 1115 waiver, not counted in totals.

[4] All means hourly or daily limits on all services or waivers.

NOTE: HCBS is home and community-based services.

SOURCE: Interviews with State Officials of Waiver Programs in 1998-1999.

two of its waivers (MR/DD and medically fragile children) but maintained individual cost caps for the remainder. These individual cost caps were determined using the relative institutional costs for each population targeted. Some States set individual cost caps at a percentage of comparable institutional costs. Consequently, caps on allowable costs varied considerably across waivers within and across States.

Formal limits on the number of hours per day or days per week of waiver services were less common. Only two States, Michigan and Utah, reported codified lim-

its on service use in all waivers (Table 2). More than one-half of the States (31) had no formal service limits, however, 19 enforced limits on at least some services or in at least one waiver (Table 2). In Georgia, for example, there was the stipulation in the MR/DD waiver that the State would not pay for more than 6 hours per day of day habilitation service. Kansas had stricter service limits (12 hours per day) in the frail elderly waiver than in its other waivers. In Oklahoma's MR/DD waiver, there were time limits on each waiver service, but in its aged and disabled waiver, the use of individual cost caps sufficed to limit service use. In Minnesota, there were not only formal limits on the use of select services but also on various combinations of services. Similarly, in Rhode Island, which had only one formal service limitation, there was a 30-hour limit on homemaker and personal care services combined per week in the elderly waiver. Moreover, formal service limits might be expressed in different metrics. In Kentucky, individual waiver services were limited either in units (i.e., hours or other time increments) or in dollars (creating a different type of cost cap).

Program Implementation and Monitoring

Table 3 presents data regarding the use of case management in the Medicaid 1915(c) waiver program. Case management, or care coordination in some form, was generally an available service in the HCBS waiver program, offered in all but 10 States as a specific waiver service, excluding Arizona and Washington, DC, which did not have 1915(c) waivers in 1997-1998. Table 3 shows that case management by means of the waivers represented an average expenditure of $1.67 per capita in 1997. This average was 4.6 percent of total HCBS waiver services in l997.

Many States offered case management services through a State plan optional benefit (i.e., "targeted case management"). Statute defines targeted case management services as "services which assist an individual eligible under the plan in gaining access to needed medical, social, educational and other services." (42 U.S.C. 1396n (g) (1)). States are allowed to reach out beyond the bounds of the Medicaid program to coordinate a broad range of activities and services necessary to the optional functioning of a Medicaid client (Health Care Financing Administration, 2000). These data do not allow one to discern the ways in which targeted case management may or may not differ from case management offered via other funding streams.

The average per capita expenditures for targeted case management services was $5.39 per capita in 1997. All except six States provided targeted case management services, but detailed data regarding who received those services were unavailable. There was variation, unmeasured in these data, across States as well as between waivers within States, in the use of these two types of case management services for Medicaid participants. Moreover, data regarding the degree to which States financed case management as a component of Medicaid administrative expenses were also unavailable. The lack of complete data on the full range of case management options exercised by the States suggests that the statistics presented in Table 3 may be underestimated.

Most States did not allow participants the option of refusing case management services because the States consider it to be an integral part of their HCBS waiver programs. Some States reported that case managers were responsible for authorizing services, setting service limits, supervising providers, and assessing quality. In 11

Table 3

Medicaid Case Management Expenditures, by State: 1997-1998

State	Total Waiver Expenditures per Capita	Case Management Expenditures in Waivers per Capita	Waiver Case Management as Percent of Total Waiver Expenditures	Targeted Case Management Expenditures per Capita	Total Case Management Expenditures per Capita	Total Case Management as Percent of Waiver Expenditures
Vermont	$96.22	$13.78	14.30	$17.40	$31.18	32.40
Massachusetts	46.81	—	—	30.77	30.77	65.70
Oregon	69.12	—	—	19.29	19.29	27.90
Maine	55.47	0.28	0.50	18.08	18.36	33.10
Tennessee	13.33	1.07	8.00	16.77	17.84	133.80
Minnesota	66.60	3.66	5.50	14.14	17.80	26.70
South Carolina	25.47	1.34	5.20	15.06	16.39	64.40
West Virginia	46.97	6.65	14.20	7.92	14.57	31.00
Michigan	21.33	2.21	10.40	11.45	13.66	64.10
North Carolina	32.98	3.00	9.10	9.19	12.19	37.00
Georgia	13.54	0.33	2.40	11.39	11.72	86.60
New York	75.85	4.47	5.90	5.06	9.54	12.60
Washington[1]	37.96	—	—	9.36	9.36	24.70
Mississippi	3.94	0.63	15.90	8.44	9.07	230.00
New Mexico	58.13	—	—	8.98	8.98	15.40
North Dakota	51.62	1.99	3.80	6.42	8.41	16.30
Wisconsin	55.25	4.25	7.70	3.76	8.01	14.50
Wyoming	76.82	7.52	9.80	0.43	7.95	10.30
Alabama	24.29	1.40	5.80	6.06	7.46	30.70
Texas	17.87	2.02	11.30	5.32	7.34	41.10
Pennsylvania	31.53	1.03	3.30	6.14	7.17	22.70
Missouri	34.61	0.01	0.00	6.46	6.47	18.70
Idaho[1]	11.52	—	—	6.14	6.14	53.30
Montana[1]	41.11	2.75	6.70	2.77	5.52	13.40
New Hampshire	84.32	4.40	5.20	1.12	5.52	6.60
Utah	26.46	1.38	5.20	4.13	5.51	20.80
Connecticut[1]	78.77	1.86	2.40	3.63	5.49	7.00
Kentucky	19.03	1.93	10.10	3.49	5.42	28.50
Iowa	19.51	—	—	5.25	5.25	26.90
South Dakota	52.59	5.17	9.80	—	5.17	9.80
Hawaii[1]	17.72	1.97	11.10	3.08	5.05	28.50
Florida	12.69	1.56	12.30	2.47	4.03	31.80
Alaska	37.65	2.89	7.70	—	2.89	7.70
Rhode Island	94.19	1.03	1.10	1.85	2.88	3.10
Kansas	59.48	0.81	1.40	1.93	2.74	4.60
Delaware	28.30	2.63	9.30	—	2.63	9.30
Oklahoma	27.30	—	—	2.30	2.30	8.40
Arkansas[1]	13.76	0.21	1.60	1.95	2.17	15.80
Nebraska	38.98	—	—	1.78	1.78	4.60
Ohio[1]	16.30	—	—	1.77	1.77	10.90
New Jersey	31.77	1.17	3.70	0.28	1.45	4.60
Illinois	20.96	—	—	1.40	1.40	6.70
Maryland[1]	28.80	1.00	3.50	0.11	1.10	3.80
Louisiana	11.51	0.03	0.30	0.86	0.90	7.80

See footnotes at end of table.

Table 3—Continued

Medicaid Case Management Expenditures, by State: 1997-1998

State	Total Waiver Expenditures per Capita	Case Management Expenditures in Waiver per Capita	Waiver Case Management as Percent of Total Waiver Expenditures	Targeted Case Management Expenditures per Capita	Total Case Management Expenditures per Capita	Total Case Management as Percent of Waiver Expenditures
California[1]	$14.07	$0.60	$4.30	$0.24	$0.84	$6.00
Nevada[1]	5.63	0.71	12.60	-	0.71	12.60
Indiana	6.53	0.45	6.80	0.08	0.53	8.00
Virginia[1]	23.94	0.04	0.10	0.44	0.48	2.00
Colorado	44.09	0.06	0.10	0.34	0.40	0.90
Arizona[2]	—	—	—	—	—	—
Washington, DC[3]	—	—	—	—	—	—
Average	29.40	1.67	4.60	5.39	6.70	22.40

[1]Clients can opt not to use case management and still receive 1915 (c) waiver services.

[2]Medicaid 1115 waiver.

[3]Waivers not yet active.

SOURCES: Harrington, C., Carrillo, H., Wellin, V., et al.: Home and Community-Based Waivers in the States 1992-1997. San Francisco, CA. University of California. 1999; Health Care Financing Administration: Medical Assistance Payments and Administration Expenditures, Form 64. 1999.

States, as noted in Table 3, waiver participants were allowed the option of refusing case management oversight.

Table 3 also compares the States in terms of their overall expenditures on case management for their Medicaid programs. Total case management expenditures per capita include expenditures in the 1915(c) waivers and those for targeted case management in the optional State plan. Eleven States spent more than $10 per capita on case management in these two Medicaid programs combined; the average was $6.70 per capita. This was 23 percent of the total 1915(c) waiver expenditures in 1997. In Tennessee and Mississippi, case management expenditures were larger than overall waiver expenditures. In others, case management expenditures amounted to more than one-half as much as was spent on the waivers in total (Massachusetts, South Carolina, Michigan, Georgia, and Idaho).

Formal Client Satisfaction and Quality Assessment

Two ways of monitoring waiver services are the development of tools for assessing client satisfaction and the creation of organizational structures devoted to the assessment of service quality. Officials from 67 percent of the States described some type of client satisfaction survey (not shown). Surveys were typically conducted by telephone or mail and occasionally in person or some combination thereof. Seventy-eight percent of the States incorporated some type of formal quality assessment into their program management. In response to questions about monitoring service quality, many officials reported that quality assessment was part of the case managers' ongoing responsibilities.

Existing client satisfaction and quality assessment efforts tended to be limited to specific waivers or administering agencies, varying across them, and only sporadically implemented on relatively small numbers of program participants. In Iowa, for instance, for the TBI and MR waivers, extensive outcome-based surveys were carried out, which involved face-to-face interviews with a random sample of clients conducted by a survey team. In 1998-1999, these efforts were part of a pilot project funded by the Robert Wood Johnson Foundation. In contrast, for Iowa's AIDS waiver, assessment activities were limited to a paper review of care plans followed up with random telephone calls to selected clients. Officials in Iowa planned to extend outcome-based surveys to all waivers in the future.

It was also not uncommon for monitoring efforts to be left to provider agencies, instead of carried out directly by the administering government agency. For example, in Georgia, the Division of Aging required that all direct service agencies used in its elderly and disabled waiver program evaluate participant satisfaction and service quality on an annual basis. Although the Division of Aging monitored this process, the agencies were left to their own devices in designing such assessments. These data do not allow us to discern the relative costs and benefits of such arrangements for evaluating waiver services nationwide.

Finally, State officials had difficulty specifying the degree to which they formally assessed client satisfaction or service quality. Some reported these activities were components of case management. For the purposes of this research, States without clearly defined mechanisms extending beyond case management were not counted as initiating formalized and targeted satisfaction or quality assessment. In this respect, we underestimate their occurrence. However, because we credited all States that operated some targeted assessment mechanism, regardless of its scope,

breadth, or administering agency, we simultaneously overestimate the occurrence of these activities.

DISCUSSION

In 1998-1999, there were active Medicaid 1915(c) HCBS waivers in 49 States and Washington, DC, serving more than 500,000 persons. The waiver program nationwide has grown steadily since its inception (Harrington et al., 2000a). Despite being widespread, however, the program remained small in relation to those offering institutional placement. Medicaid 1915(c) waiver participants were 32 percent of the Medicaid participants in institutional care in 1997. In addition, HCFA Form 64 data on Medicaid expenditures show that HCBS, of which the waivers are one program, collectively represent a small proportion of spending on nursing home and ICF-MR care (Burwell, 1999). Some portion of this difference in program expenditures is attributable to the fact that Medicaid institutional costs include expenses associated with the provision of room and board, whereas Medicaid HCBS regulations prohibit room and board payments. Nonetheless, such variation in both participants and expenditures is clearly cause for more targeted studies of costs across the various long-term care (LTC) benefits, as well as for examinations of current spending levels and their consequences.

Although researchers have invested considerable effort studying how many participants receive waiver services and at what costs (Burwell, 1999; Harrington et al., 2000a; Miller, Ramsland, and Harrington, 1999), little has been written concerning the programmatic and administrative structures that support this complex Federal-State benefit program. These data demonstrated that waiver administration is dispersed across a number of government agencies and divisions within States. The existing network of waiver programs and administering agencies observable in many States appeared to be primarily shaped by each State's organizational structure for health and human services as well as on where program expertise is available.

Perhaps most important was the fact that waivers were targeted toward groups of individuals categorized on the basis of characteristics that distinguish them (e.g., diagnostic labels), rather than on needs they share with others requiring LTC. Most States had multiple agencies administering waiver services to multiple target groups. It was not clear what the relative costs or benefits are of duplicating processes across agencies or departments versus creating a single point of administrative activity. There was already some evidence to suggest States are moving toward the latter. Oregon, for instance, reported streamlining the administration of its HCBS waiver programs into two agencies. Initiatives to encourage waiver consolidation may be welcomed by additional States (e.g., New York, Texas, and Wisconsin), while other States may prefer the current structure. In addition, some States are considering the placement of Medicaid HCBS under managed care (e.g., Delaware, Georgia, Hawaii, Kentucky, Nebraska, Oklahoma, and Wisconsin) (Harrington et al., 2000d). As these administrative changes evolve across the country, additional study will be needed to track and assess their impact on administrative efficiency, costs, and client outcomes.

These data also showed that, despite their ultimate authority over the 1915(c) HCBS waiver program, State Medicaid offices were structurally removed from the day-to-day work involved in implementing many waivers. Only 64 of the 234 active

waivers (27 percent) in 1998-1999 were administered directly by a State office of Medicaid. This finding raises concerns because it suggests that the State officials ultimately responsible for the fate of these programs are often isolated from the front lines of care. Recent indepth studies of selected State 1915(c) waiver programs found that much of the initiative, innovation, and leadership concerning HCBS waivers resided outside of Medicaid. Moreover, there was site-visit evidence to suggest that some State Medicaid offices act primarily to control costs (Harrington, LeBlanc, and Tonner, 1999). Further study is required to assess the generalizability of these findings.

Further research is needed to learn more about the role of State Medicaid offices in the development and maintenance of the 1915(c) waivers program. Little is known about the day-to-day relationships between various State offices and related agencies in managing their LTC programs. Perhaps even less is known about the historical, political, and social contexts of these relationships (Harrington et al., 2000e, 2000f, 2000g; Newcomer et al., 2000a, 2000b). Once analysts are able to more fully describe these administrative arrangements across States and the powerful social forces that shape them, they should also strive to develop methods for linking them to the size, scope, and quality of HCBS programs such as the 1915(c) waivers.

These data also offer clear illustration of how a few States limit financial eligibility for Medicaid waiver services. State financial eligibility for HCBS services was generally the same as the eligibility for individuals living in nursing facilities or ICFs-MR. However, financial eligibility criteria for waiver benefits in seven States were more restrictive than those for institutional placement, creating an explicit bias away from HCBS. These States also set different financial eligibility criteria for different waivers, creating inequities across groups targeted for waiver services. The effects of these financial eligibility rules on program participants and on those consequently denied service have not been studied, highlighting a gap in HCBS research.

One policy option would be for Federal policymakers to consider a statutory change requiring the States to use the same financial eligibility criteria for institutional care and HCBS. Although this approach would increase costs in some States, it would reduce the inherent institutional bias. Alternatively, Congress might consider financial initiatives that encourage the States to use the 300 percent of SSI maximum income level for Medicaid 1915(c) waiver eligibility for both categorically and medically needy individuals.

We also found that, once participants were enrolled in the program, States imposed limitations on service use, sometimes by setting formal limits, but more uniformly by imposing cost caps. Fifteen States have enforced cost limits only in the aggregate and have still demonstrated cost-neutrality. This approach appeared to be more liberal and generous than the use of individual cost caps used in other States, however, this may not be the case, as at least some States use only a percentage of comparable institutional costs in setting aggregate cost caps (complete data unavailable). In addition to enforcing cost limits on individual participants, some States enacted extra cost controls by formalizing specific limits on given waivers or specific waiver services. By using different cost controls for different waiver target groups, the States may contribute to large differences in spending across populations (Harrington et al., 2000a). Although different groups may have different needs and expenses, the consequences of such

differential spending remain to be systematically studied. Moreover, given the fundamental cost-containment mechanisms built into waiver policy, it is unclear whether additional limits in State policies are of practical use. Unfortunately, such variations in waiver policy are difficult to study because they are used contemporaneously with other administrative arrangements.

Case management was provided in all States (no data presented for Arizona and Washington, DC, which did not have waivers in l997-1998) either in the 1915(c) waiver or through the targeted case management program. The available data did not allow for a complete description of the substance and influence of case management across waivers. Nonetheless, according to the conservative estimates drawn from these data, Medicaid-funded case management expenditures in the waiver program and targeted case management expenditures were equal to 22.4 percent of the total 1915(c) waiver program expenditures. It is not clear whether case management services were cost-effective for waiver recipients. Especially when viewed in light of the States' demonstrated efforts to contain costs, numerous questions regarding the multifaceted role of case managers in the 1915(c) waivers program should be addressed by future research: What is the role of the HCBS case manager? To what extent are they simply gatekeepers to services? Under what circumstances are they useful to clients across waiver populations? With the rapid growth of consumer-directed models of care, these issues await additional study.

These data also showed that formal, targeted assessments of client satisfaction and service quality were not uniformly conducted with regard to waiver services. According to numerous State officials, these activities were generally considered to be part of the case manager's role, however, it was unknown whether their work entailed systematic, meaningful, and indepth assessments of client satisfaction and care quality. Further study is required to examine the role of case management in the conduct of such assessments. Is there an inherent conflict between these tasks and the role of gatekeeper to service? Federal and State policymakers should begin evaluating ways to assess client satisfaction and service quality beyond the basic oversight of care coordination and case management.

Nearly two decades after their inception, Medicaid 1915(c) waivers account for the largest proportion of formal LTC in the home and community for low-income Americans (Burwell, 1999). As a benefit program, the waivers have, in a sense, come of age. With their widespread implementation, appeal among the general public, and recent advances of the disability rights movement (e.g., U.S. Supreme Court decision in *Olmstead* v. *L.C.*, 119 S. Ct. 2176 (1999)), the time appears ripe for rapid expansion. However, in response to Federal 1915(c) waiver statutes and regulations that (1) target special populations and geographical areas; (2) allow States to use more restrictive financial eligibility criteria for the waivers than for institutional care; and (3) require cost-neutrality, the States have created program structures that inherently limit growth, such as cost ceilings and hourly limits on services. If the HCBS programs are to be expanded, as is the stated goal of HCFA, then structural and policy barriers that may limit the program require a careful examination.

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